



ILLINOIS  
HOSPICE &  
PALLIATIVE CARE  
ORGANIZATION



GREATER  
ILLINOIS PEDIATRIC  
PALLIATIVE CARE  
COALITION

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The Office of Governor Pat Quinn  
Attention: Michael Gelder  
Chairman of the Health Care Reform Implementation Council  
207 State House  
Springfield, IL 62706

September 19, 2012

Dear Mr. Gelder:

On behalf of the Illinois Hospice and Palliative Care Organization (IL-HPCO) and the Greater Illinois Pediatric Palliative Care Coalition (GIPPCC), I write to submit recommendations for consideration as Illinois formulates its plan for the Health Exchange Program in our state. We appreciate your efforts to solicit input from provider organizations. This letter addresses hospice care and pediatric palliative care services.

### **Hospice**

Hospice is a comprehensive model of care, focused on providing quality and compassionate services to patients facing life threatening and terminal conditions. Hospice provides expert medical care, pain management and emotional and spiritual support, expressly tailored to the patient's needs and wishes. While hospice services are typically provided in a patient's home, they may also be provided in inpatient facilities, nursing homes or other long-term care facilities.

Although hospice was not specifically enumerated in the list of 10 categories of coverage under Section 1302 of the Affordable Care Act (ACA), it is an integral component in the healthcare continuum. Patients receiving hospice services at the end of life are less likely to be hospitalized during the final 30 days of life, are more likely to receive pain management, and families have higher overall satisfaction rates with the care their loved one has received. In addition to the meaningful quality of life benefits, a study out of Duke University indicated that those patients receiving hospice services at the end of life spent an average of \$2,300 less Medicaid dollars per beneficiary, as compared with those individuals that did not receive hospice support.

The IOM Committee review of federal health insurance programs notes that hospice is a covered service under the Medicare statute. Moreover, the Department of Labor (DOL) survey of employer plans notes that hospice is also widely offered under private health insurance plans. According to the DOL report, hospice care is mentioned in 66 percent of large employer plan materials and in 69 percent of small employer plan documents.



Additionally, Mercer reported 91 percent of employers were offering hospice and all 3 large insurers polled by the IOM committee (CIGNA, United and Wellpoint) indicated it was covered service.

### **Pediatric Palliative Care**

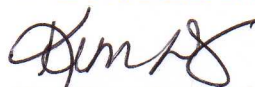

Children with potentially life limiting illnesses benefit tremendously from the provision of community-based, pediatric palliative care services. Pediatric palliative care seeks to relieve symptoms associated with a serious medical condition or its treatment and to enhance the quality of life for children and their families by addressing psychological, social and spiritual needs. Typically, a pediatric palliative care program is facilitated by a hospice organization, due to the experience of these professionals in addressing life-limiting and potential end-of-life issues. Services often include in-home coordination of family-centered care, access to 24/7 nursing support, respite care, expressive therapies and family counseling.

State-based public programming for pediatric palliative care is beginning to emerge throughout the country. California began operating a pediatric palliative care program for Medicaid beneficiaries during 2009. A recent policy report reviewing the California program indicated that palliative support increased quality of life for families; most notably, families reported an increase in confidence when caring for their child, a decrease in sleep difficulty and a decrease in anxiety. Additionally, however, this program demonstrated significant cost savings through a shift to increased community service utilization. Specifically, children involved in California's pediatric palliative care programming demonstrated a one-third reduction in the average number of days spent in the hospital, leading to an average cost saving of \$1,677 per child per month (11% reduction in spending on a traditionally high cost population).

The American Academy of Pediatrics recommends that pediatric palliative care begin upon the diagnosis of a child's life threatening condition and continue alongside curative or life-saving treatment, through bereavement services, if the child does not survive. Moreover, the Institute of Medicine recommends that palliative care for children be incorporated into both public and private insurance plans.

In consideration of the above noted information, particularly the increased quality of life and cost-saving benefits of hospice and pediatric palliative care, it is our recommendation that these services be incorporated into the Health Exchange program benefits in Illinois. Please feel warmly welcomed to contact Rick Kasper, Chair, Legislative Committee, IL-HPCO at rkasper@Joliethospice.org or via phone at (815 ) 740-4104 or Kim Downing RN, JD, Program Coordinator, GIPPCC at kdowning@horizonhospice.org or via phone at (312) 733-8900 x 393 with any questions.

With Gratitude for your Consideration,

   
Kim Downing and Rick Kasper

*The mission of the IL-HPCO is to expand access to exceptional hospice and palliative care for patients and families coping with the close of life experience.*

*The mission of GIPPCC to collaborate with its members to educate, advocate for, and partner with consumers, healthcare providers and the community in order to improve and increase access to palliative care and bereavement services for children and families throughout Illinois.*